Agency for Healthcare Research and Quality
Advancing Excellence in Health Care

NATIONAL GUIDELINE CLEARINGHOUSE

General

Guideline Title

Autism: recognition, referral, diagnosis and management of adults on the autism spectrum.

Bibliographic Source(s)

National Institute for Health and Clinical Excellence (NICE). Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 Jun. 57 p. (Clinical guideline; no. 142).

Guideline Status

This is the current release of the guideline.

Recommendations

Major Recommendations

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Mental Health (NCCMH) on behalf of the National Institute for Health and Clinical Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance.

General Principles of Care

Principles for Working with Adults with Autism and Their Families, Partners and Carers

All staff working with adults with autism should:

- Work in partnership with adults with autism and, where appropriate, with their families, partners and carers
- Offer support and care respectfully
- Take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care.

All staff working with adults with autism should have an understanding of the:

- Nature, development and course of autism
- Impact on personal, social, educational and occupational functioning
- Impact of the social and physical environment

All health and social care professionals providing care and support for adults with autism should have a broad understanding of the:

- Nature, development and course of autism

- Impact on personal, social, educational and occupational functioning
- Impact of and interaction with the social and physical environment
- Impact on and interaction with other coexisting mental and physical disorders and their management
- Potential discrepancy between intellectual functioning as measured by intelligence quotient (IQ) and adaptive functioning as reflected, for example, by difficulties in planning and performing activities of daily living including education or employment.

All health and social care professionals providing care and support for adults with autism should:

- Aim to foster the person's autonomy, promote active participation in decisions about care and support self-management
- Maintain continuity of individual relationships wherever possible
- Ensure that comprehensive information about the nature of, and interventions and services for, their difficulties is available in an appropriate language or format (including various visual, verbal and aural, easy-read, and different colour and font formats)
- Consider whether the person may benefit from access to a trained advocate

All health and social care professionals providing care and support for adults with autism and their families, partners and carers should:

- Ensure that they are easily identifiable (for example, by producing or wearing appropriate identification) and approachable
- Clearly communicate their role and function
- Address the person using the name and title they prefer
- Clearly explain any clinical language and check that the person with autism understands what is being said
- Take into account communication needs, including those arising from a learning disability, sight or hearing problems or language difficulties, and provide communication aids or independent interpreters (someone who does not have a personal relationship with the person with autism) if required.

All health and social care professionals providing care and support for adults with autism and their families, partners and carers should ensure that they are:

- Familiar with recognised local and national sources (organisations and websites) of information and/or support for people with autism
- Able to discuss and advise on how to access and engage with these resources.

Encourage adults with autism to participate in self-help or support groups or access one-to-one support, and provide support so that they can attend meetings and engage in the activities.

In all settings, take into account the physical environment in which adults with autism are assessed, supported and cared for, including any factors that may trigger challenging behaviour. If necessary make adjustments or adaptations to the:

- Amount of personal space given (at least an arm's length)
- Setting using visual supports (for example, use labels with words or symbols to provide visual cues about expected behaviour)
- Colour of walls and furnishings (avoid patterns and use low-arousal colours such as cream)
- Lighting (reduce fluorescent lighting, use blackout curtains or advise use of dark glasses or increase natural light)
- Noise levels (reduce external sounds or advise use of earplugs or ear defenders)

Where it is not possible to adjust or adapt the environment, consider varying the duration or nature of any assessment or intervention (including taking regular breaks) to limit the negative impact of the environment.

All health and social care professionals providing care and support for adults with autism should:

- Be aware of under-reporting and under-recognition of physical disorders in people with autism
- Be vigilant for unusual likes and dislikes about food and/or lack of physical activity
- Offer advice about the beneficial effects of a healthy diet and exercise, taking into account any hyper- and/or hypo-sensory sensitivities; if necessary, support referral to a general practitioner (GP) or dietician.

All staff working with adults with autism should be sensitive to issues of sexuality, including asexuality and the need to develop personal and sexual relationships. In particular, be aware that problems in social interaction and communication may lead to the person with autism misunderstanding another person's behaviour or to their possible exploitation by others.

Ensure that adults with autism who have caring responsibilities receive support to access the full range of mental and physical health and social care services, including:

- Specific information, advice and support to parents about their parenting role, including parent training if needed, by professionals experienced in the care of adults and children with autism
- Social support, such as childcare, to enable them to attend appointments, groups and therapy sessions, and to access education and employment.

Structures for the Organisation and Delivery of Care and Interventions

In order to effectively provide care and support for adults with autism, the local autism multi-agency strategy group (see the NGC summary of Autism: recognition, referral and diagnosis of children and young people on the autism spectrum, NICE clinical guideline 128) should include representation from managers, commissioners and clinicians from adult services, including mental health, learning disability, primary healthcare, social care, housing, educational and employment services, the criminal justice system and the third sector. There should be meaningful representation from people with autism and their families, partners and carers.

In each area a specialist community-based multidisciplinary team for adults with autism (the specialist autism team) should be established. The membership should include:

- Clinical psychologists
- Nurses
- Occupational therapists
- Psychiatrists
- Social workers
- Speech and language therapists
- Support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills)

The specialist autism team should have a key role in the delivery and coordination of:

- Specialist diagnostic and assessment services
- Specialist care and interventions
- Advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team)
- Support in accessing, and maintaining contact with, housing, educational and employment services
- Support to families, partners and carers where appropriate
- Care and interventions for adults with autism living in specialist residential accommodation
- Training, support and consultation for staff who care for adults with autism in residential and community settings

Involving Families, Partners and Carers

Discuss with adults with autism if and how they want their families, partners or carers to be involved in their care. During discussions, take into account any implications of the Mental Capacity Act (2005) and any communication needs the person may have.

If the person with autism wants their family, partner or carer(s) to be involved, encourage this involvement and:

- Negotiate between the person with autism and their family, partner or carer(s) about confidentiality and sharing of information on an ongoing basis
- Explain how families, partners and carers can help support the person with autism and help with care plans
- Make sure that no services are withdrawn because of involvement of the family, partner or carer(s), unless this has been clearly agreed with both the person with autism and their family, partner or carer(s)

Give all families, partners and carer(s) (whether or not the person wants them to be involved in their care) verbal and written information about:

- Autism and its management
- Local support groups and services specifically for families, partners and carers
- Their right to a formal carer's assessment of their own physical and mental health needs, and how to access this

If a person with autism does not want their family, partners or carer(s) to be involved in their care:

- Give the family, partner or carer(s) verbal and written information about who they can contact if they are concerned about the person's care
- Bear in mind that people with autism may be ambivalent or negative towards their family or partner. This may be for many different reasons,

including a coexisting mental disorder or prior experience of violence or abuse

<u>Identification and Assessment</u>

Principles for the Effective Assessment of Autism

Staff who have responsibility for the identification or assessment of adults with autism should adapt these procedures, if necessary, to ensure their effective delivery, including modifications to the setting in which assessment is delivered and the duration and pacing of the assessment.

Identification and Initial Assessment of Possible Autism

Consider assessment for possible autism when a person has:

- One or more of the following:
    - Persistent difficulties in social interaction
    - Persistent difficulties in social communication
    - Stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, and
- One or more of the following:
    - Problems in obtaining or sustaining employment or education
    - Difficulties in initiating or sustaining social relationships
    - Previous or current contact with mental health or learning disability services
    - A history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder

For adults with possible autism who do not have a moderate or severe learning disability, consider using the Autism-Spectrum Quotient – 10 items (AQ-10) (Allison, Auyeung, & Baron-Cohen, 2012). (If a person has reading difficulties, read out the AQ-10.) If a person scores above six on the AQ-10, or autism is suspected based on clinical judgement (taking into account any past history provided by an informant), offer a comprehensive assessment for autism.

For adults with possible autism who have a moderate or severe learning disability, consider a brief assessment to ascertain whether the following behaviours are present (if necessary using information from a family member, partner or carer):

- Difficulties in reciprocal social interaction including:
    - Limited interaction with others (for example, being aloof, indifferent or unusual)
    - Interaction to fulfil needs only
    - Interaction that is naive or one-sided
- Lack of responsiveness to others
- Little or no change in behaviour in response to different social situations
- Limited social demonstration of empathy
- Rigid routines and resistance to change
- Marked repetitive activities (for example, rocking and hand or finger flapping), especially when under stress or expressing emotion

If two or more of the above categories of behaviour are present, offer a comprehensive assessment for autism.

Comprehensive (Diagnostic, Needs and Risks) Assessment of Suspected Autism

A comprehensive assessment should:

- Be undertaken by professionals who are trained and competent
- Be team-based and draw on a range of professions and skills
- Where possible involve a family member, partner, carer or other informant or use documentary evidence (such as school reports) of current and past behaviour and early development

At the beginning of a comprehensive assessment, discuss with the person the purpose of the assessment and how the outcome of the assessment will be fed back to them. Feedback should be individualised, and consider involving a family member, partner, carer or advocate, where appropriate, to support the person and help explain the feedback.

During a comprehensive assessment, enquire about and assess the following:

- Early developmental history, where possible

- Behavioural problems
- Functioning at home, in education or in employment
- Past and current physical and mental disorders
- Other neurodevelopmental conditions
- Hyper- and/or hypo-sensory sensitivities and attention to detail

Carry out direct observation of core autism signs and symptoms especially in social situations.

To aid more complex diagnosis and assessment for adults, consider using a formal assessment tool, such as:

- The following tools for people who do not have a learning disability:
  - The Adult Asperger Assessment (AAA; includes the Autism-Spectrum Quotient [AQ] and the Empathy Quotient [EQ]) (Baron-Cohen et al., 2005)
  - The Autism Diagnostic Interview – Revised (ADI-R) (Lord et al., 1997)
  - The Autism Diagnostic Observation Schedule – Generic (ADOS-G) (Lord et al., 2000)
  - The Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI) (Gillberg et al., 2001)
  - The Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R) (Ritvo et al., 2011)
- The following tools in particular for people with a learning disability:
  - The ADOS-G
  - The ADI-R

To organise and structure the process of a more complex assessment, consider using a formal assessment tool, such as the Diagnostic Interview for Social and Communication Disorders (DISCO) (Wing et al., 2002), the ADOS-G or the ADI-R.

During a comprehensive assessment, take into account and assess for possible differential diagnoses and coexisting disorders or conditions, such as:

- Other neurodevelopmental conditions (use formal assessment tools for learning disabilities)
- Mental disorders (for example, schizophrenia, depression or other mood disorders, and anxiety disorders, in particular, social anxiety disorder and obsessive–compulsive disorder)
- Neurological disorders (for example, epilepsy)
- Physical disorders
- Communication difficulties (for example, speech and language problems, and selective mutism)
- Hyper- and/or hypo-sensory sensitivities

Do not use biological tests, genetic tests or neuroimaging for diagnostic purposes routinely as part of a comprehensive assessment.

During a comprehensive assessment, assess the following risks:

- Self-harm (in particular in people with depression or a moderate or severe learning disability)
- Rapid escalation of problems
- Harm to others
- Self-neglect
- Breakdown of family or residential support
- Exploitation or abuse by others

Develop a risk management plan if needed.

Develop a care plan based on the comprehensive assessment, incorporating the risk management plan and including any particular needs (such as adaptations to the social or physical environment), and also taking into account the needs of the family, partner or carer(s).

Provide a 'health passport' (for example, a laminated card) for adults with autism, which includes information for all staff about the person's care and support needs. Advise the person to carry the health passport at all times.

As part of a comprehensive assessment consider developing a 24-hour crisis management plan, where necessary in conjunction with specialist mental health services, which should detail:

- The likely trigger(s) for a crisis
- The nature and speed of the reaction to any trigger(s), including details about the way in which autism may impact on a person's behaviour

leading up to and during a crisis

- The role of the specialist team and other services (including outreach and out-of-hours services) in responding to a crisis
- Advice to primary care professionals and other services on their responsibilities and appropriate management in a crisis
- Advice for families, partners and carers about their role in a crisis
- The nature of any changes or adaptations to the social or physical environment needed to manage a crisis (see recommendations under "General Principles of Care" above

Consider obtaining a second opinion (including referral to another specialist autism team if necessary), if there is uncertainty about the diagnosis or if any of the following apply after diagnostic assessment:

- Disagreement about the diagnosis within the autism team
- Disagreement with the person, their family, partner, carer(s) or advocate about the diagnosis
- A lack of local expertise in the skills and competencies needed to reach diagnosis in adults with autism
- The person has a complex coexisting condition, such as a severe learning disability, a severe behavioural, visual, hearing or motor problem, or a severe mental disorder (see the NGC summary Autism: recognition, referral and diagnosis of children and young people on the autism spectrum, NICE clinical guideline 128).

On an individual basis, and using information from the comprehensive assessment and physical examination, and clinical judgement, consider further investigations, including:

- Genetic tests, as recommended by the regional genetics centre, if there are specific dysmorphic features, congenital anomalies and/or evidence of a learning disability
- Electroencephalography if there is suspicion of epilepsy
- Hearing or sight tests, if there is suspicion of hearing or visual impairment
- Other medical tests depending on individual signs and symptoms (for example, sudden onset of challenging behaviour, change in usual patterns of behaviour, sudden change in weight, or suspicion that the person might be in pain and is unable to communicate this).

Offer all adults who have received a diagnosis of autism (irrespective of whether they need or have refused further care and support) a follow-up appointment to discuss the implications of the diagnosis, any concerns they have about the diagnosis, and any future care and support they may require.

Assessment of Challenging Behaviour

Assessment of challenging behaviour should be integrated into a comprehensive assessment for adults with autism.

When assessing challenging behaviour carry out a functional analysis (see recommendations under "Interventions for Challenging Behaviour" below) including identifying and evaluating any factors that may trigger or maintain the behaviour, such as:

- Physical disorders
- The social environment (including relationships with family members, partners, carers and friends)
- The physical environment, including sensory factors
- Coexisting mental disorders (including depression, anxiety disorders and psychosis)
- Communication problems
- Changes to routines or personal circumstances

Identifying the Correct Interventions and Monitoring Their Use

When discussing and deciding on interventions with adults with autism, consider:

- Their experience of, and response to, previous interventions
- The nature and severity of their autism
- The extent of any associated functional impairment arising from the autism, a learning disability or a mental or physical disorder
- The presence of any social or personal factors that may have a role in the development or maintenance of any identified problem(s)
- The presence, nature, severity and duration of any coexisting disorders
- The identification of predisposing and possible precipitating factors that could lead to crises if not addressed (see the NGC summary Common mental health disorders. Identification and pathways to care, NICE clinical guideline 123).

When discussing and deciding on care and interventions with adults with autism, take into account the:

- Increased propensity for elevated anxiety about decision-making in people with autism
- Greater risk of altered sensitivity and unpredictable responses to medication
- Environment, for example whether it is suitably adapted for people with autism, in particular those with hyper- and/or hypo-sensory sensitivities (see recommendations under "General Principles of Care" above)
- Presence and nature of hyper- and/or hypo-sensory sensitivities and how these might impact on the delivery of the intervention
- Importance of predictability, clarity, structure and routine for people with autism
- Nature of support needed to access interventions

When discussing and deciding on interventions with adults with autism, provide information about:

- The nature, content and duration of any proposed intervention
- The acceptability and tolerability of any proposed intervention
- Possible interactions with any current interventions and possible side effects
- The implications for the continuing provision of any current interventions (see the NGC summary Common mental health disorders. Identification and pathways to care, NICE clinical guideline 123).

When deciding on options for pharmacological interventions for challenging behaviour or coexisting mental disorders in adults with autism:

- Be aware of the potential for greater sensitivity to side effects and idiosyncratic responses in people with autism and
- Consider starting with a low dose

For any intervention used in adults with autism, there should be a regular review of:

- The benefits of the intervention, where feasible using a formal rating of the target behaviour(s)
- Any adverse events
- Specific monitoring requirements of pharmacological interventions as highlighted by the summary of product characteristics
- Adherence to the intervention

Interventions for Autism

Psychosocial Interventions for the Core Symptoms of Autism

For adults with autism without a learning disability or with a mild to moderate learning disability, who have identified problems with social interaction, consider:

- A group-based social learning programme focused on improving social interaction
- An individually delivered social learning programme for people who find group-based activities difficult

Social learning programmes to improve social interaction should typically include:

- Modelling
- Peer feedback (for group-based programmes) or individual feedback (for individually delivered programmes)
- Discussion and decision-making
- Explicit rules
- Suggested strategies for dealing with socially difficult situations

Do not provide 'facilitated communication' for adults with autism.

Psychosocial Interventions Focused on Life Skills

For adults with autism of all ranges of intellectual ability, who need help with activities of daily living, consider a structured and predictable training programme based on behavioural principles.

For adults with autism without a learning disability or with a mild to moderate learning disability, who are socially isolated or have restricted social contact, consider:

- A group-based structured leisure activity programme
- An individually delivered structured leisure activity programme for people who find group-based activities difficult

A structured leisure activity programme should typically include:

- A focus on the interests and abilities of the participant(s)
- Regular meetings for a valued leisure activity
- For group-based programmes, a facilitator with a broad understanding of autism to help integrate the participants
- The provision of structure and support

For adults with autism without a learning disability or with a mild to moderate learning disability, who have problems with anger and aggression, offer an anger management intervention, adjusted to the needs of adults with autism.

Anger management interventions should typically include:

- Functional analysis of anger and anger-provoking situations
- Coping-skills training and behaviour rehearsal
- Relaxation training
- Development of problem-solving skills

For adults with autism without a learning disability or with a mild learning disability, who are at risk of victimisation, consider anti-victimisation interventions based on teaching decision-making and problem-solving skills.

Anti-victimisation interventions should typically include:

- Identifying and, where possible, modifying and developing decision-making skills in situations associated with abuse
- Developing personal safety skills

For adults with autism without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment, consider an individual supported employment programme.

An individual supported employment programme should typically include:

- Help with writing CVs and job applications and preparing for interviews
- Training for the identified work role and work-related behaviours
- Carefully matching the person with autism with the job
- Advice to employers about making reasonable adjustments to the workplace
- Continuing support for the person after they start work
- Support for the employer before and after the person starts work, including autism awareness training

Biomedical (Pharmacological, Physical and Dietary) Interventions and the Core Symptoms of Autism

Do not use anticonvulsants for the management of core symptoms of autism in adults.

Do not use chelation for the management of core symptoms of autism in adults.

Do not use the following interventions for the management of core symptoms of autism in adults:

- Exclusion diets (such as gluten- or casein-free and ketogenic diets)
- Vitamins, minerals and dietary supplements (such as vitamin B6 or iron supplementation)

Do not use drugs specifically designed to improve cognitive functioning (for example, cholinesterase inhibitors) for the management of core symptoms of autism or routinely for associated cognitive or behavioural problems in adults.

Do not use oxytocin for the management of core symptoms of autism in adults.

Do not use secretin for the management of core symptoms of autism in adults.

Do not use testosterone regulation for the management of core symptoms of autism in adults.

Do not use hyperbaric oxygen therapy for the management of core symptoms of autism in adults.

Do not use antipsychotic medication for the management of core symptoms of autism in adults.

Do not use antidepressant medication for the routine management of core symptoms of autism in adults.

Interventions for Challenging Behaviour

Before initiating other interventions for challenging behaviour, address any identified factors that may trigger or maintain the behaviour (see recommendations under "Identification and Assessment" above) by offering:

- The appropriate care for physical disorders (for example, gastrointestinal problems or chronic pain)
- Treatment for any coexisting mental disorders, including psychological and pharmacological interventions (for example, anxiolytic, antidepressant or antipsychotic medication), informed by existing NICE guidance
- Interventions aimed at changing the physical or social environment (for example, who the person lives with) when problems are identified, such as:
    - Advice to the family, partner or carer(s)
    - Changes or accommodations to the physical environment (see recommendations under "General Principles of Care" above)

Offer a psychosocial intervention for the challenging behaviour first if no coexisting mental or physical disorder, or problem related to the physical or social environment, has been identified as triggering or maintaining challenging behaviour.

When deciding on the nature and content of a psychosocial intervention to address challenging behaviour, use a functional analysis. The functional analysis should facilitate the targeting of interventions that address the function(s) of problem behaviour(s) by:

- Providing information, from a range of environments, on:
    - Factors that appear to trigger the behaviour
    - The consequences of the behaviour (that is, the reinforcement received as a result of their behaviour [reinforcement may be by the person with autism or those working with or caring for them])
- Identifying trends in behaviour occurrence, factors that may be evoking that behaviour, and the needs that the person is attempting to meet by performing the behaviour

In addition to the functional analysis, base the choice of intervention(s) on:

- The nature and severity of the behaviour
- The person's physical needs and capabilities
- The physical and social environment
- The capacity of staff and families, partners or carers to provide support
- The preferences of the person with autism and, where appropriate, their family, partner or carer(s)
- Past history of care and support

Psychosocial Interventions for Challenging Behaviour

Psychosocial interventions for challenging behaviour should be based on behavioural principles and informed by a functional analysis of behaviour (see recommendations above).

Psychosocial interventions for challenging behaviour should include:

- Clearly identified target behaviour(s)
- A focus on outcomes that are linked to quality of life
- Assessment and modification of environmental factors that may contribute to initiating or maintaining the behaviour
- A clearly defined intervention strategy
- A clear schedule of reinforcement, and capacity to offer reinforcement promptly and contingently on demonstration of the desired behaviour
- A specified timescale to meet intervention goals (to promote modification of intervention strategies that do not lead to change within a specified time)
- A systematic measure of the target behaviour(s) taken before and after the intervention to ascertain whether the agreed outcomes are being met

Combined Interventions for Challenging Behaviour

Consider antipsychotic medication* in conjunction with a psychosocial intervention for challenging behaviour when there has been no or limited response to psychosocial or other interventions (such as environmental adaptations). Antipsychotic medication should be prescribed by a specialist and quality of life outcomes monitored carefully. Review the effects of the medication after 3–4 weeks and discontinue it if there is no indication of a clinically important response at 6 weeks.

Pharmacological Interventions for Challenging Behaviour

Consider antipsychotic medication* for challenging behaviour on its own when psychosocial or other interventions could not be delivered because of the severity of the challenging behaviour. Antipsychotic medication should be prescribed by a specialist and quality of life outcomes monitored carefully. Review the effects of the medication after 3–4 weeks and discontinue it if there is no indication of a clinically important response at 6 weeks.

Do not routinely use anticonvulsants for the management of challenging behaviour in adults with autism.

*At the time of publication (June 2012), no antipsychotic medication had a UK marketing authorisation for this indication in adults with autism. Informed consent should be obtained and documented.

<u>Interventions for Coexisting Mental Disorders</u>

Staff delivering interventions for coexisting mental disorders to adults with autism should:

- Have an understanding of the core symptoms of autism and their possible impact on the treatment of coexisting mental disorders
- Consider seeking advice from a specialist autism team regarding delivering and adapting these interventions for people with autism

Psychosocial Interventions for Coexisting Mental Disorders

For adults with autism and coexisting mental disorders, offer psychosocial interventions informed by existing NICE guidance for the specific disorder.

Adaptations to the method of delivery of cognitive and behavioural interventions for adults with autism and coexisting common mental disorders should include:

- A more concrete and structured approach with a greater use of written and visual information (which may include worksheets, thought bubbles, images and 'tool boxes')
- Placing greater emphasis on changing behaviour, rather than cognitions, and using the behaviour as the starting point for intervention
- Making rules explicit and explaining their context
- Using plain English and avoiding excessive use of metaphor, ambiguity and hypothetical situations
- Involving a family member, partner, carer or professional (if the person with autism agrees) to support the implementation of an intervention
- Maintaining the person's attention by offering regular breaks and incorporating their special interests into therapy if possible (such as using computers to present information)

Pharmacological Interventions for Coexisting Mental Disorders

For adults with autism and coexisting mental disorders, offer pharmacological interventions informed by existing NICE guidance for the specific disorder.

<u>Assessment and Interventions for Families, Partners and Carers</u>

Offer families, partners and carers of adults with autism an assessment of their own needs including:

- Personal, social and emotional support
- Support in their caring role, including respite care and emergency plans
- Advice on and support in obtaining practical support
- Planning of future care for the person with autism

When the needs of families, partners and carers have been identified, provide information about, and facilitate contact with, a range of support groups including those specifically designed to address the needs of families, partners and carers of people with autism.

Offer information, advice, training and support to families, partners and carers if they:

- Need help with the personal, social or emotional care of the family member, partner or friend, or
- Are involved in supporting the delivery of an intervention for their family member, partner or friend (in collaboration with professionals)

<u>Organisation and Delivery of Care</u>

Developing Local Care Pathways

Local care pathways should be developed to promote implementation of key principles of good care. Pathways should be:

- Negotiable, workable and understandable for adults with autism, their families, partners and carers, and professionals
- Accessible and acceptable to all people in need of the services served by the pathway
- Responsive to the needs of adults with autism and their families, partners and carers
- Integrated so that there are no barriers to movement between different levels of the pathway
- Outcome focused (including measures of quality, service user experience and harm) (see the NGC summary Common mental health disorders. Identification and pathways to care, NICE clinical guideline 123).

Autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include:

- Developing clear policy and protocols for the operation of the pathway
- Ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway
- Making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services
- Supporting the integrated delivery of services across all care settings
- Supporting the smooth transition to adult services for young people going through the pathway
- Auditing and reviewing the performance of the pathway (see the NGC summary Common mental health disorders. Identification and pathways to care, NICE clinical guideline 123)

The autism strategy group should develop local care pathways that promote access to services for all adults with autism, including:

- People with coexisting physical and mental disorders (including substance misuse)
- Women
- People with learning disabilities
- Older people
- People from black and minority ethnic groups
- Transgender people
- Homeless people
- People from the traveller community
- People in the criminal justice system
- Parents with autism

When providing information about local care pathways to adults with autism and their families, partners and carers, all professionals should:

- Take into account the person's knowledge and understanding of autism and its care and management
- Ensure that such information is appropriate to the communities using the pathway (see the NGC summary of Common mental health disorders. Identification and pathways to care, NICE clinical guideline 123).

The autism strategy group should design local care pathways that promote a range of evidence-based interventions at each step in the pathway and support adults with autism in their choice of interventions (see the NGC summary of Common mental health disorders. Identification and pathways to care, NICE clinical guideline 123).

The autism strategy group should design local care pathways that respond promptly and effectively to the changing needs of all populations served by the pathways. Pathways should have in place:

- Clear and agreed goals for the services offered to adults with autism
- Robust and effective means for measuring and evaluating the outcomes associated with the agreed goals
- Clear and agreed mechanisms for responding promptly to identified changes to people's needs (see the NGC summary Common mental health disorders. Identification and pathways to care, NICE clinical guideline 123).

The autism strategy group should design local care pathways that provide an integrated programme of care across all care settings. Pathways should:

- Minimise the need for transition between different services or providers
- Allow services to be built around the pathway and not the pathway around the services
- Establish clear links (including access and entry points) to other care pathways (including those for physical healthcare needs)
- Have designated staff who are responsible for the coordination of people's engagement with the pathway (see the NGC summary Common

[mental health disorders. Identification and pathways to care,](#) NICE clinical guideline 123).

Improving Access to Care

There should be a single point of referral (including self-referral) to specialist services for adults with autism.

Support access to services and increase the uptake of interventions by:

- Delivering assessment and interventions in a physical environment that is appropriate for people with hyper- and/or hypo-sensory sensitivities (see recommendations under "General Principles of Care" above)
- Changing the professional responsible for the person's care if a supportive and caring relationship cannot be established.

Support access to services and increase the uptake of interventions by:

- Ensuring systems (for example, care coordination or case management) are in place to provide for the overall coordination and continuity of care for adults with autism
- Designating a professional to oversee the whole period of care (usually a member of the primary healthcare team for those not in the care of a specialist autism team or mental health or learning disability service) (see the NGC summary [Common mental health disorders. Identification and pathways to care,](#) NICE clinical guideline 123).

Residential Care

If residential care is needed for adults with autism it should usually be provided in small, local community-based units (of no more than six people and with well-supported single person accommodation). The environment should be structured to support and maintain a collaborative approach between the person with autism and their family, partner or carer(s) for the development and maintenance of interpersonal and community living skills.

Residential care environments should include activities that are:

- Structured and purposeful
- Designed to promote integration with the local community and use of local amenities
- Clearly timetabled with daily, weekly and sequential programmes that promote choice and autonomy

Residential care environments should have:

- Designated areas for different activities that provide visual cues about expected behaviour
- Adaptations to the physical environment for people with hyper- and/or hypo-sensory sensitivities (see recommendations under "General Principles of Care" above)
- Inside and outside spaces where the person with autism can be alone (for example, if they are over-stimulated).

Residential care staff should:

- Understand the principles and attitudes underpinning the effective delivery of residential care for adults with autism
- Work in collaboration with health and community care staff from a range of specialist services to support the delivery of a comprehensive care plan
- Be trained in assessing and supporting the needs of adults with autism
- Be consistent and predictable, but with some flexibility to allow change and choice
- Be committed to involving families, partners and carers

Clinical Algorithm(s)

A NICE pathway for autism is available from the [National Institute for Health and Clinical Excellence (NICE) Web site](#) _____.

Scope

Disease/Condition(s)

Autism spectrum disorders encompassing autism, Asperger's syndrome and atypical autism (or pervasive developmental disorder not otherwise specified)

Guideline Category

Diagnosis

Evaluation

Management

Screening

Clinical Specialty

Family Practice

Internal Medicine

Neurology

Psychiatry

Psychology

Speech-Language Pathology

Intended Users

Advanced Practice Nurses

Health Care Providers

Nurses

Occupational Therapists

Patients

Pharmacists

Physician Assistants

Physicians

Psychologists/Non-physician Behavioral Health Clinicians

Social Workers

Speech-Language Pathologists

Guideline Objective(s)

To make recommendations for the recognition, referral, diagnosis and management of adults on the autism spectrum

Target Population

- Adults and young people aged 18 years and older with suspected autism across the range of diagnostic groups

- Families, partners and carers of patients with autism

Interventions and Practices Considered

General Principles of Care

1. Principles of care for staff working with adults with autism and their families, partners and carers
2. Structures for the organisation and delivery of care and interventions
3. Involving families, partners and carers in care

Identification and Assessment

1. Identification and initial assessment of possible autism (e.g., use of Autism-Spectrum Quotient–10)
2. Comprehensive (diagnostic, needs and risks) assessment of suspected autism using formal assessment tools
3. Assessment of challenging behavior
4. Identifying the correct interventions and monitoring their use

Interventions for Autism

1. Psychosocial interventions for the core symptoms of autism
2. Psychosocial interventions focused on life skills
3. Biomedical (pharmacological, physical and dietary) interventions for the core symptoms of autism (considered but not recommended)

Interventions for Challenging Behavior

1. Psychosocial interventions for challenging behavior
2. Combined interventions for challenging behaviour (e.g., antipsychotics combined with psychosocial interventions)
3. Pharmacological interventions for challenging behaviour

Interventions for Coexisting Mental Disorders

1. Psychosocial interventions for coexisting mental disorders
2. Pharmacological interventions for coexisting mental disorders

Assessment and Interventions for Families, Partners, and Carers

1. Personal, social and emotional support
2. Support in their caring role, including respite care and emergency plans
3. Advice on and support in obtaining practical support
4. Planning of future care for the person with autism

Organization and Delivery of Care

1. Developing local care pathways
2. Improving access to care
3. Providing residential care

Major Outcomes Considered

- Sensitivity, specificity, positive and negative predictive value of diagnostic and screening tools
- Social interaction
- Communication
- Repetitive behaviour
- Overall autistic behaviour
- Symptom severity/improvement
- Quality of life
- Side effects

- Coexisting conditions
- Cost effectiveness

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Searches of Unpublished Data

Description of Methods Used to Collect/Select the Evidence

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Mental Health (NCCMH) on behalf of the National Institute for Health and Clinical Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance.

Systematic Clinical Literature Review

The aim of the clinical literature review was to systematically identify and synthesise relevant evidence from the literature in order to answer the specific review questions developed by the Guideline Development Group (GDG).

Methodology

A stepwise, hierarchical approach was taken to locating and presenting evidence to the GDG. The NCCMH developed this process based on methods set out by NICE (The Guidelines Manual [NICE, 2009e]; see the "Availability of Companion Documents" field), and after considering recommendations from a range of other sources. These included:

- British Medical Journal (BMJ) Clinical Evidence
- Clinical Policy and Practice Program of the New South Wales Department of Health (Australia)
- The Cochrane Collaboration
- Grading of Recommendations: Assessment, Development, and Evaluation (GRADE) Working Group
- New Zealand Guidelines Group
- National Health Service (NHS) Centre for Reviews and Dissemination (CRD)
- Oxford Centre for Evidence-Based Medicine
- Oxford Systematic Review Development Programme
- Scottish Intercollegiate Guidelines Network
- United States Agency for Healthcare Research and Quality

The Review Process

Scoping Searches

A broad preliminary search of the literature was undertaken in January 2010 to obtain an overview of the issues likely to be covered by the scope, and to help define key areas. Searches were restricted to clinical guidelines, Health Technology Assessment (HTA) reports, key systematic reviews and randomised controlled trials (RCTs) and conducted in a number of databases and websites (see the full version of the original guideline for specific databases and websites searched).

Other relevant guidelines were assessed for quality using the Appraisal of Guidelines for Research and Evaluation (AGREE) instrument (AGREE Collaboration, 2003). The evidence base underlying high-quality existing guidelines was utilised and updated as appropriate. Further information about this process can be found in *The Guidelines Manual* (NICE, 2009e).

Systematic Literature Searches

After the scope was finalised, a systematic search strategy was developed to locate all the relevant evidence. The balance between sensitivity (the power to identify all studies on a particular topic) and specificity (the ability to exclude irrelevant studies from the results) was carefully considered, and a decision made to utilise a broad approach to searching to maximise retrieval of evidence to all parts of the guideline. Searches were restricted to systematic reviews, RCTs, observational studies, case series, quasi-experimental studies, qualitative and survey research, and conducted in the following databases:

- Allied and Complementary Medicine (AMED)
- Applied Social Services Index and Abstracts (ASSIA)
- Australian Education Index (AEI)
- British Education Index (BEI)
- CDSR
- CENTRAL
- CINAHL
- DARE
- Education Resources in Curriculum (ERIC)
- Embase
- HMIC
- HTA database
- International Bibliography of Social Science (IBSS)
- MEDLINE/MEDLINE In-Process
- PsycBOOKS
- PsycEXTRA
- Psychological Information Database (PsycINFO)
- Sociological Abstracts
- Social Services Abstracts (SSA)

The search strategies were initially developed for MEDLINE before being translated for use in other databases/interfaces. Strategies were built up through a number of trial searches and discussions of the results of the searches with the review team and GDG to ensure that all possible relevant search terms were covered. In order to assure comprehensive coverage, search terms for autism were kept purposely broad to help counter dissimilarities in database indexing practices and thesaurus terms, and imprecise reporting of study populations by authors in the titles and abstracts of records. In the absence of good-quality evidence on autism, additional searching was conducted for wider literature on learning disabilities. The search terms for each search are set out in full in Appendix 9 of the full version of the original guideline (see the "Availability of Companion Documents" field).

Reference Manager

Citations from each search were downloaded into the reference management software and duplicates removed. Records were then screened against the eligibility criteria of the reviews before being quality appraised. The unfiltered search results were saved and retained for future potential re-analysis to help keep the process both replicable and transparent.

Search Filters

To aid retrieval of relevant and sound studies, filters were used to limit a number of searches to systematic reviews, RCTs, observational studies, case series, quasi-experimental studies, qualitative and survey research. The search filters for systematic reviews and RCTs are adaptations of filters designed by the Health Information Research Unit of McMaster University. The remaining filters used were developed in-house. Each filter comprises index terms relating to the study type(s) and associated textwords for the methodological description of the design(s).

Date and Language Restrictions

Systematic database searches were initially conducted in November 2010 up to the most recent searchable date. Search updates were generated on a 6-monthly basis, with the final re-runs carried out in September 2011 ahead of the guideline consultation. After this point, studies were only included if they were judged by the GDG to be exceptional (for example, if the evidence was likely to change a recommendation).

Although no language restrictions were applied at the searching stage, foreign language papers were not requested or reviewed, unless they were of particular importance to a review question.

Date restrictions were not applied.

Other Search Methods

Other search methods involved: (a) scanning the reference lists of all eligible publications (systematic reviews, stakeholder evidence and included studies) for more published reports and citations of unpublished research; (b) sending lists of studies meeting the inclusion criteria to subject experts (identified through searches and the GDG) and asking them to check the lists for completeness, and to provide information of any published or unpublished research for consideration (see Appendix 6 of the full version of the original guideline); (c) checking the tables of contents of key journals for studies that might have been missed by the database and reference list searches; (d) tracking key papers in the Science Citation Index (prospectively) over time for further useful references.

Full details of the search strategies and filters used for the systematic review of clinical evidence are provided in Appendix 9 of the full version of the original guideline.

Study Selection

All primary-level studies included after the first scan of citations were acquired in full and re-evaluated for eligibility at the time they were being entered into the study information database. More specific eligibility criteria were developed for each review question and are described in the relevant clinical evidence chapters.

Search Strategy for Economic Evidence

Scoping Searches

A broad preliminary search of the literature was undertaken in January 2010 to obtain an overview of the issues likely to be covered by the scope, and help define key areas. Searches were restricted to economic studies and health technology assessment reports.

Any relevant economic evidence arising from the clinical scoping searches was also made available to the health economist during the same period.

Systematic Literature Searches

After the scope was finalised, a systematic search strategy was developed to locate all the relevant evidence. The balance between sensitivity (the power to identify all studies on a particular topic) and specificity (the ability to exclude irrelevant studies from the results) was carefully considered, and a decision made to utilise a broad approach to searching to maximise retrieval of evidence to all parts of the guideline. Searches were restricted to economic studies and health technology assessment reports, and conducted in the following databases:

- EconLit
- HTA database
- Embase
- MEDLINE/MEDLINE In-Process
- NHS EED
- PsycINFO

In addition, Google and Google Scholar were also searched for any research potentially missed by the electronic database searches.

Any relevant economic evidence arising from the clinical searches was also made available to the health economist during the same period. For standard mainstream bibliographic databases (Embase, MEDLINE and PsycINFO) search terms for autism were combined with a search filter for health economic studies. For searches generated in topic-specific databases (EconLit, HTA, NHS EED) search terms for autism were used without a filter. The sensitivity of this approach was aimed at minimising the risk of overlooking relevant publications, due to potential weaknesses resulting from more focused search strategies. A more focused approach was employed for searches on learning disabilities. The search terms are set out in full in Appendix 11 of the full version of the original guideline.

Further details of the search strategies and filter used for the systematic review of health economic evidence are provided in Section 3.6.1 and Appendix 11 of the full version of the original guideline. Inclusion criteria are provided in Section 3.6.2 of the full version of the guideline. For results of the systematic search of economic literature refer to Section 3.6.5.

Number of Source Documents

- Experience of care of adults with autism - 14 studies
- Experience of families, partners and carers of adults with autism - 14 studies
- Case identification tools - 9 studies

- Autism assessment instruments - 11 articles
- Health economic evidence - 1 study and an economic model

Methods Used to Assess the Quality and Strength of the Evidence

Expert Consensus

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

The quality of the evidence was based on the quality assessment components (study design, limitations to study quality, consistency, directness and any other considerations) and graded using the following definitions:

- High - Further research is very unlikely to change the confidence in the estimate of the effect.
- Moderate - Further research is likely to have an important impact on the confidence in the estimate of the effect and may change the estimate.
- Low - Further research is very likely to have an important impact on the confidence in the estimate of the effect and is likely to change the estimate.
- Very low - Any estimate of effect is very uncertain.

Methods Used to Analyze the Evidence

Meta-Analysis

Review of Published Meta-Analyses

Systematic Review with Evidence Tables

Description of the Methods Used to Analyze the Evidence

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Mental Health (NCCMH) on behalf of the National Institute for Health and Clinical Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance.

Clinical Effectiveness

Study Selection and Quality Assessment

All primary-level studies included after the first scan of citations were acquired in full and re-evaluated for eligibility at the time they were being entered into the study information database. More specific eligibility criteria were developed for each review question and are described in the relevant clinical evidence chapters. Eligible systematic reviews and primary-level studies were critically appraised for methodological quality (see Appendix 10 in the full version of the original guideline for methodology checklists). The eligibility of each study was confirmed by at least one member of the appropriate topic group.

For some review questions, it was necessary to prioritise the evidence with respect to the UK context (that is, external validity). To make this process explicit, the topic groups took into account the following factors when assessing the evidence:

- Participant factors (for example, gender, age and ethnicity)
- Provider factors (for example, model fidelity, the conditions under which the intervention was performed and the availability of experienced staff to undertake the procedure)
- Cultural factors (for example, differences in standard care and differences in the welfare system).

It was the responsibility of each topic group to decide which prioritisation factors were relevant to each review question in light of the UK context and then decide how they should modify their recommendations.

The Guideline Development Group (GDG) used a number of criteria when deciding whether or not to accept unpublished data. First, the evidence must have been accompanied by a trial report containing sufficient detail to properly assess the quality of the data. Second, the evidence must have been submitted with the understanding that data from the study and a summary of the study's characteristics would be published in the full guideline. Therefore, the GDG did not accept evidence submitted as commercial in confidence. However, the GDG recognised that unpublished evidence submitted by investigators might later be retracted by those investigators if the inclusion of such data would jeopardise publication of their research.

Data Extraction

Quantitative Analysis

Study characteristics and outcome data were extracted from all eligible studies that met the minimum quality criteria, using Review Manager 5.1 (see Appendix 14 in the full version of the original guideline).

In most circumstances, for a given outcome (continuous and dichotomous), where more than 50% of the number randomised to any group were missing or incomplete, the study results were excluded from the analysis (except for the outcome 'leaving the study early', in which case, the denominator was the number randomised). Where there were limited data for a particular review, the 50% rule was not applied. In these circumstances the evidence was downgraded due to the risk of bias.

Where possible, outcome data from an intention-to-treat (ITT) analysis (that is, a 'once-randomised-always-analyse' basis) was used. For dichotomous efficacy outcomes the effect size was re-calculated if ITT had not been used. When making the calculations if there was good evidence that those participants who ceased to engage in the study were likely to have an unfavourable outcome, early withdrawals were included in both the numerator and denominator. Adverse effects were entered into Review Manager as reported by the study authors because it is usually not possible to determine whether early withdrawals had an unfavourable outcome.

Consultation with another reviewer or members of the GDG was used to overcome difficulties with coding. Data from studies included in existing systematic reviews were extracted independently by one reviewer and cross-checked with the existing data set. Where possible, two independent reviewers extracted data from new studies. Where double data extraction was not possible, data extracted by one reviewer was checked by the second reviewer. Disagreements were resolved through discussion. Where consensus could not be reached, a third reviewer or GDG members resolved the disagreement. Masked assessment (that is, blind to the journal from which the article comes, the authors, the institution and the magnitude of the effect) was not used since it is unclear that doing so reduces bias.

Qualitative Literature Review and Thematic Analysis

The purpose of the qualitative search was to identify qualitative evidence sources for which an analysis could be undertaken in order to identify themes relevant to the experience of autism, and the experience of services and treatment from the point of view of the service user and/or their families, partners and carers. The intention was that this thematic analysis would inform the development of recommendations about service users' experience of the condition, of care and interventions, and of the organisation and delivery of services.

For primary studies, a broad thematic analysis of individual patient data was undertaken by one reviewer; this was then discussed and developed with another reviewer. The evidence was then extracted and the themes coded independently by the two reviewers; finally the themes were checked to ensure all of the data were covered.

The results of this thematic analysis were used to develop:

- Recommendations about service users' and carers' experience of care
- Recommendations that were based on other evidence sources but where the data from the qualitative analysis could be used to provide a context for, or inform the wording or focus of, a recommendation

Synthesising the Evidence from Comparative Effectiveness Studies

Meta-analysis

Where possible, meta-analysis was used to synthesise evidence from comparative effectiveness studies using Review Manager. If necessary, re-analyses of the data or sub-analyses were used to answer review questions not addressed in the original studies or reviews.

Dichotomous outcomes were analysed as relative risks (RR) with the associated 95% confidence interval (CI) (see Figure 3 in the full version of the original guideline [see the "Availability of Companion Documents" field]) for an example of a forest plot displaying dichotomous data). An RR

(also called a risk ratio) is the ratio of the treatment event rate to the control event rate. An RR of 1 indicates no difference between treatment and control. In Figure 3, the overall RR of 0.73 indicates that the event rate (that is, non-remission rate) associated with intervention A is about three-quarters of that with the control intervention or, in other words, the RR reduction is 27%.

Continuous outcomes were analysed using the mean difference (MD), or SMD when different measures were used in different studies to estimate the same underlying effect (see Figure 4 in the full version of the original guideline for an example of a forest plot displaying continuous data). If reported by study authors, ITT data, using a valid method for imputation of missing data, were preferred over data only from people who completed the study.

Synthesising the Evidence from Diagnostic Test Accuracy Studies

Meta-analysis

Review Manager was used to summarise test accuracy data from each study using forest plots and summary receiver operating characteristic (ROC) plots.

Sensitivity and Specificity

When describing the sensitivity and specificity of the different instruments, the GDG defined values above 0.9 as 'excellent', 0.8 to 0.9 as 'good', 0.5 to 0.7 as 'moderate', 0.3 to 0.4 as 'low', and less than 0.3 as 'poor'.

Clinical Utility

The assessment instrument should be feasible and implementable in routine clinical care across a variety of assessment settings. The time and skills required to administer, score and interpret the instrument was also considered, as well as the cost and any copyright issues.

Evaluating Psychometric Data for Diagnostic Test Accuracy Studies

In addition to sensitivity and specificity measures, other psychometric properties of case identification and assessment instruments that met inclusion criteria were evaluated according to the following criteria.

- Reliability:
  - Inter-rater reliability
  - Test-retest reliability
  - Internal consistency
- Validity:
  - Criterion validity
  - Construct validity

Presenting the Data to the Guideline Development Group

Study characteristics tables and, where appropriate, forest plots generated with Review Manager were presented to the GDG. The Grading of Recommendations: Assessment, Development, and Evaluation (GRADE) approach was used to grade the quality of evidence and strength of recommendations. The technical team produced GRADE evidence profiles (see below) using the GRADE profiler software, and summary of findings tables were presented to the GDG.

Where meta-analysis was not appropriate and/or possible, the reported results from each primary-level study were included in the study characteristics table. The range of effect estimates were included in the GRADE profile, and where appropriate, described narratively.

Evidence Profile Tables

A GRADE evidence profile was used to summarise both the quality of the evidence and the results of the evidence synthesis (see Table 3 in the full version of the original guideline for an example of an evidence profile). The GRADE approach is based on a sequential assessment of the quality of evidence, followed by judgment about the balance between desirable and undesirable effects, and subsequent decision about the strength of a recommendation.

Within the GRADE approach to quality of evidence, the following is used as a starting point:

- RCTs without important limitations provide high-quality evidence
- Observational studies without special strengths or important limitations provide low-quality evidence

For each outcome, quality may be reduced depending on the following factors: limitations, inconsistency, indirectness, imprecision, publication bias.

For observational studies, the quality may be up-graded if there is a large effect, all plausible confounding would reduce the demonstrated effect (or increase the effect if no effect was observed), or there is evidence of a dose-response gradient (details would be provided under the 'other' column). Each evidence profile also included a summary of the findings: number of participants included in each group, an estimate of the magnitude of the effect, and the overall quality of the evidence for each outcome.

Refer to Section 3.5 in the full version of the original guideline document (see the "Availability of Companion Documents" field) for more information on methods used to analyze the evidence.

<u>Health Economics Methods</u>

The aim of the health economics was to contribute to the guideline's development by providing evidence on the cost effectiveness of interventions for adults with autism covered in the guideline. This was achieved by:

- Systematic literature review of existing economic evidence
- Decision-analytic economic modelling

Systematic reviews of economic literature were conducted in all areas covered in the guideline. Economic modelling was undertaken in areas with likely major resource implications, where the current extent of uncertainty over cost effectiveness was significant and economic analysis was expected to reduce this uncertainty, in accordance with The Guidelines Manual (NICE, 2009e; see the "Availability of Companion Documents" field). Prioritisation of areas for economic modelling was a joint decision between the Health Economist and the GDG. The rationale for prioritising review questions for economic modelling was set out in an economic plan agreed between NICE, the GDG, the Health Economist and the other members of the technical team. An economic model was therefore developed to address the cost effectiveness of an employment support programme versus usual standard service for adults with autism.

In addition, literature on the health-related quality of life of people with autism was systematically searched to identify studies reporting appropriate utility scores that could be utilised in a cost-utility analysis.

Applicability and Quality Criteria for Economic Studies

All economic papers eligible for inclusion were appraised for their applicability and quality using the methodology checklist for economic evaluations recommended by NICE (NICE, 2009e), which is shown in Appendix 12 of the full version of the original guideline. The methodology checklist for economic evaluations was also applied to the economic model developed specifically for this guideline. Studies that fully or partially met the applicability and quality criteria described in the methodology checklist were considered during the guideline development process, along with the results of the economic modelling conducted specifically for this guideline. The completed methodology checklists for all economic evaluations considered in the guideline are provided in Appendix 17 of the full version of the original guideline.

Methods Used to Formulate the Recommendations

Expert Consensus

Informal Consensus

Description of Methods Used to Formulate the Recommendations

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Mental Health (NCCMH) on behalf of the National Institute for Health and Clinical Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance.

The Guideline Development Group (GDG)

The GDG consisted of: professionals in psychiatry, clinical psychology, nursing, social work, and general practice; academic experts in psychiatry and psychology; a service user and carers, and a representative from a service user organisation. The guideline development process was supported by staff from the NCCMH, who undertook the clinical and health economic literature searches, reviewed and presented the evidence to the GDG, managed the process, and contributed to drafting the guideline.

Guideline Development Group Meetings

Twelve GDG meetings were held between 27 July 2010 and 7 September 2011. During each day-long GDG meeting, in a plenary session, review questions and clinical and economic evidence were reviewed and assessed, and recommendations formulated.

Topic Groups

The GDG divided its workload along clinically relevant lines to simplify the guideline development process, and GDG members formed smaller topic groups to undertake guideline work in that area of clinical practice. Topic group 1 covered questions relating to assessment and case identification. Topic group 2 covered psychological/educational/social interventions. Topic groups 3 and 4 covered biomedical interventions and experience of care, respectively. These groups were designed to efficiently manage evidence appraisal prior to presenting it to the GDG as a whole. Each topic group was chaired by a GDG member with expert knowledge of the topic area (one of the healthcare professionals). Topic groups refined the review questions and the clinical definitions of interventions, reviewed and prepared the evidence with the systematic reviewer before presenting it to the GDG as a whole, and helped the GDG to identify further expertise in the topic. Topic group leaders reported the status of the group's work as part of the standing agenda. They also introduced and led the GDG's discussion of the evidence review for that topic and assisted the GDG Chair in drafting the section of the guideline relevant to the work of each topic group.

Service Users and Carers

Individuals with direct experience of services gave an integral service-user focus to the GDG and the guideline. The GDG included a service user and carers, and a representative from a service user organisation. They contributed as full GDG members to writing the review questions, helping to ensure that the evidence addressed their views and preferences, highlighting sensitive issues and terminology relevant to the guideline, and bringing service-user research to the attention of the GDG. In drafting the guideline, they met with the NCCMH team to develop the chapter on experience of care, they contributed to writing the guideline's introduction and identified recommendations from the service user and carer perspective.

National and International Experts

National and international experts in the area under review were identified through the literature search and through the experience of the GDG members. These experts were contacted to identify unpublished or soon-to-be published studies, to ensure that up-to-date evidence was included in the development of the guideline. They informed the GDG about completed trials at the pre-publication stage, systematic reviews in the process of being published, studies relating to the cost effectiveness of treatment and trial data if the GDG could be provided with full access to the complete trial report. Appendix 6 in the full version of the original guideline lists researchers who were contacted.

Review Questions

Review (clinical) questions were used to guide the identification and interrogation of the evidence base relevant to the topic of the guideline. Before the first GDG meeting, an analytic framework (see Appendix 7 in the full version of the original guideline) was prepared by NCCMH staff based on the scope and an overview of existing guidelines, and discussed with the guideline Chair. The framework was used to provide a structure from which the review questions were drafted. Both the analytic framework and the draft review questions were then discussed by the GDG at the first few meetings and amended as necessary. Where appropriate, the framework and questions were refined once the evidence had been searched and, where necessary, sub-questions were generated. Questions submitted by stakeholders were also discussed by the GDG and the rationale for not including any questions was recorded in the minutes. The final list of review questions can be found in Appendix 7 of the full version of the original guideline.

For questions about interventions, the PICO (population, intervention, comparison and outcome) framework was used (see Table 1 in the full version of the original guideline).

From Evidence to Recommendations

Once the clinical and health economic evidence was summarised, the GDG drafted the recommendations. In making recommendations, the GDG took into account the trade-off between the benefits and harms of the intervention/instrument, as well as other important factors, such as economic considerations, values of the development group and society, the requirements to prevent discrimination and to promote equality, and the GDG's awareness of practical issues.

Finally, to show clearly how the GDG moved from the evidence to the recommendations, each chapter has a section called 'from evidence to recommendations'. Underpinning this section is the concept of the 'strength' of a recommendation. This takes into account the quality of the evidence but is conceptually different. Some recommendations are 'strong' in that the GDG believes that the vast majority of healthcare professionals and service users would choose a particular intervention if they considered the evidence in the same way that the GDG has. This is generally the case if the benefits clearly outweigh the harms for most people and the intervention is likely to be cost effective. However, there is often a closer balance between benefits and harms, and some service users would not choose an intervention whereas others would. This may

happen, for example, if some service users are particularly averse to some side effect and others are not. In these circumstances the recommendation is generally weaker, although it may be possible to make stronger recommendations about specific groups of service users. The strength of each recommendation is reflected in the wording of the recommendation, rather than by using ratings, labels or symbols. Where the GDG identified areas in which there are uncertainties or where robust evidence was lacking, they developed research recommendations. Those that were identified as 'high priority' were developed further in the NICE version of the guideline, and presented in Appendix 13 of the full version of the original guideline.

Method Used to Answer a Review Question in the Absence of Appropriately Designed, High-Quality Research

In the absence of appropriately designed, high-quality research, or where the GDG were of the opinion (on the basis of previous searches or their knowledge of the literature) that there was unlikely to be such evidence, an informal consensus process was adopted.

Informal Consensus

The starting point for the process of informal consensus was that a member of the topic group identified, with help from the systematic reviewer, a narrative review that most directly addressed the review question. Where this was not possible, a brief review of the recent literature was initiated.

This existing narrative review or new review was used as a basis for beginning an iterative process to identify lower levels of evidence relevant to the review question and to lead to written statements for the guideline. The process involved a number of steps:

1. A description of what is known about the issues concerning the clinical question was written by one of the topic group members.
2. Evidence from the existing review or new review was then presented in narrative form to the GDG and further comments were sought about the evidence and its perceived relevance to the review question.
3. Based on the feedback from the GDG, additional information was sought and added to the information collected. This may include studies that did not directly address the review question but were thought to contain relevant data.
4. If, during the course of preparing the report, a significant body of primary-level studies (of appropriate design to answer the question) were identified, a full systematic review was done.
5. At this time, subject possibly to further reviews of the evidence, a series of statements that directly addressed the review question were developed.
6. Following this, on occasions and as deemed appropriate by the GDG, the report was then sent to appointed experts outside the GDG for peer review and comment. The information from this process was then fed back to the GDG for further discussion of the statements.
7. Recommendations were then developed and could also be sent for further external peer review.
8. After this final stage of comment, the statements and recommendations were again reviewed and agreed upon by the GDG.

Refer to Sections 3.3, 3.4, and 3.5 in the full version of the original guideline (see the "Availability of Companion Documents" field) for additional information.

Rating Scheme for the Strength of the Recommendations

Not applicable

Cost Analysis

Presentation of Economic Evidence

The economic evidence considered in the guideline is provided in the respective evidence chapters of the full version of the original guideline, following presentation of the relevant clinical evidence. The references to the included studies and the respective evidence tables with the study characteristics and results are provided in Appendix 18 of the full version of the guideline. Methods and results of economic modelling undertaken alongside the guideline development process are presented in the relevant evidence chapters. Characteristics and results of all economic studies considered during the guideline development process (including modelling studies conducted for this guideline) are summarised in economic evidence profiles accompanying respective Grading of Recommendations Assessment, Development and Evaluation (GRADE) clinical evidence profiles in Appendix 19 of the full version of the original guideline.

Method of Guideline Validation

External Peer Review

Internal Peer Review

Description of Method of Guideline Validation

Registered stakeholders had an opportunity to comment on the draft guideline, which was posted on the National Institute for Health and Clinical Excellence (NICE) website during the consultation period. Following the consultation, all comments from stakeholders and others (see Appendix 5 of the full version of the original guideline) were responded to, and the guideline updated as appropriate. The Guideline Review Panel (GRP) also reviewed the guideline and checked that stakeholders' comments had been addressed.

Following the consultation period, the Guideline Development Group (GDG) finalised the recommendations and the National Collaborating Centre for Mental Health (NCCMH) produced the final documents. These were then submitted to NICE for the pre-publication check where stakeholders are given the opportunity to highlight factual errors. Any errors are corrected by the NCCMH, then the guideline was formally approved by NICE and issued as guidance to the National Health Service in England and Wales.

Evidence Supporting the Recommendations

References Supporting the Recommendations

Allison C, Auyeung B, Baron-Cohen S. Toward brief "Red Flags" for autism screening: the Short Autism Spectrum Quotient and the Short Quantitative Checklist for Autism in toddlers in 1,000 cases and 3,000 controls [corrected]. J Am Acad Child Adolesc Psychiatry. 2012 Feb;51(2):202-12. PubMed

Baron-Cohen S, Wheelwright S, Robinson J, Woodbury-Smith M. The Adult Asperger Assessment (AAA): a diagnostic method. J Autism Dev Disord. 2005 Dec;35(6):807-19. PubMed

Gillberg C, Gillberg C, Rastam M, Wentz E. The Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI): a preliminary study of a new structured clinical interview. Autism. 2001 Mar;5(1):57-66. PubMed

Lord C, Pickles A, McLennan J, Rutter M, Bregman J, Folstein S, Fombonne E, Leboyer M, Minshew N. Diagnosing autism: analyses of data from the Autism Diagnostic Interview. J Autism Dev Disord. 1997 Oct;27(5):501-17. PubMed

Lord C, Risi S, Lambrecht L, Cook EH Jr, Leventhal BL, DiLavore PC, Pickles A, Rutter M. The autism diagnostic observation schedule-generic: a standard measure of social and communication deficits associated with the spectrum of autism. J Autism Dev Disord. 2000 Jun;30(3):205-23. PubMed

Ritvo RA, Ritvo ER, Guthrie D, Ritvo MJ, Hufnagel DH, McMahon W, Tonge B, Mataix-Cols D, Jassi A, Attwood T, Eloff J. The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R): a scale to assist the diagnosis of Autism Spectrum Disorder in adults: an international validation study. J Autism Dev Disord. 2011 Aug;41(8):1076-89. PubMed

Wing L, Leekam SR, Libby SJ, Gould J, Larcombe M. The Diagnostic Interview for Social and Communication Disorders: background, inter-rater reliability and clinical use. J Child Psychol Psychiatry. 2002 Mar;43(3):307-25. PubMed

Type of Evidence Supporting the Recommendations

The type of evidence supporting the recommendations is not specifically stated.

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

Appropriate recognition, referral, diagnosis and management of adults on the autism spectrum

Potential Harms

Antipsychotics have been associated with a number of adverse effects, for instance, weight gain, diabetes, increased prolactin levels, involuntary repetitive body movements (tardive dyskinesia), extra-pyramidal side effects, and lowering of seizure threshold.

Qualifying Statements

Qualifying Statements

- This guidance represents the view of the National Institute for Health and Clinical Excellence (NICE), which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summary of product characteristics of any drugs they are considering.
- Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.
- The guideline will assume that prescribers will use a drug's summary of product characteristics (SPC) to inform decisions made with individual patients. In this guideline, drug names are marked with a footnote if they do not have a UK marketing authorisation for the indication in question at the time of publication. Prescribers should check each drug's SPC for current licensed indications.
- A number of recommendations in this guideline have been adapted from recommendations in other NICE clinical guidelines. Where this occurred, the Guideline Development Group was careful to preserve the meaning and intent of the original recommendations. Changes to wording or structure were made in order to fit the recommendations into this guideline.

Implementation of the Guideline

Description of Implementation Strategy

National Institute for Health and Clinical Excellence (NICE) has developed tools to help organisations implement this guidance (see http://guidance.nice.org.uk/CG142 [   ]; see also "Availability of Companion Documents" field).

Key Priorities for Implementation

The following recommendations have been identified as priorities for implementation.

General Principles of Care

All staff working with adults with autism should:

- Work in partnership with adults with autism and, where appropriate, with their families, partners or carers
- Offer support and care respectfully

- Take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care

In order to effectively provide care and support for adults with autism, the local autism multiagency strategy group should include representation from managers, commissioners and clinicians from adult services, including mental health, learning disability, primary healthcare, social care, housing, educational and employment services, the criminal justice system and the third sector. There should be meaningful representation from people with autism and their families, partners and carers.

Identification and Assessment

Consider assessment for possible autism when a person has:

- One or more of the following:
    - Persistent difficulties in social interaction
    - Persistent difficulties in social communication
    - Stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, and
- One or more of the following:
    - Problems in obtaining or sustaining employment or education
    - Difficulties in initiating or sustaining social relationships
    - Previous or current contact with mental health or learning disability services
    - A history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder

For adults with possible autism who do not have a moderate or severe learning disability, consider using the Autism-Spectrum Quotient – 10 items (AQ-10). (If a person has reading difficulties, read out the AQ-10.) If a person scores above six on the AQ-10, or autism is suspected based on clinical judgement (taking into account any past history provided by an informant), offer a comprehensive assessment for autism.

When assessing challenging behaviour carry out a functional analysis including identifying and evaluating any factors that may trigger or maintain the behaviour, such as:

- Physical disorders
- The social environment (including relationships with the family, partner, carer(s) and friends)
- The physical environment, including sensory factors
- Coexisting mental disorders (including depression, anxiety disorders and psychosis)
- Communication problems
- Changes to routine or personal circumstances

Interventions for Autism

For adults with autism without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment, consider an individual supported employment programme.

Organisation and Delivery of Care

Autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include:

- Developing clear policy and protocols for the operation of the pathway
- Ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway
- Making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services
- Supporting the integrated delivery of services across all care settings
- Supporting the smooth transition to adult services for young people going through the pathway
- Auditing and reviewing the performance of the pathway

Implementation Tools

Audit Criteria/Indicators

Clinical Algorithm

Patient Resources

Resources

Staff Training/Competency Material

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

Getting Better

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

National Institute for Health and Clinical Excellence (NICE). Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 Jun. 57 p. (Clinical guideline; no. 142).

Adaptation

A number of recommendations in this guideline have been adapted from recommendations in other National Institute of Health and Clinical Excellence (NICE) clinical guidelines:

- Autism: recognition, referral and diagnosis of children and young people on the autism spectrum (http://guidance.nice.org.uk/CG142)
- Common mental health disorders: identification and pathways to care (http://guidance.nice.org.uk/CG142)

Date Released

2012 Jun

Guideline Developer(s)

National Collaborating Centre for Mental Health - National Government Agency [Non-U.S.]

Source(s) of Funding

Guideline Committee

Guideline Development Group

Composition of Group That Authored the Guideline

Guideline Development Group Members: Professor Simon Baron-Cohen (*Chair, Guideline Development Group*), Director, Autism Research Centre, Psychiatry Department, University of Cambridge; Theme Lead, NIHR CLAHRC for Cambridgeshire and Peterborough NHS Foundation Trust; Professor Stephen Pilling (*Facilitator, Guideline Development Group*), Director, National Collaborating Centre for Mental Health; Director, Centre for Outcomes Research and Effectiveness, University College London; Professor Gillian Baird, Consultant Paediatrician and Professor of Paediatric Neurodisability, Guy's and St Thomas' NHS Foundation trust and King's Health partners; Dr Carole Buckley, General Practitioner, Bristol; Dr Peter Carpenter, Consultant Psychiatrist (Learning Disabilities), Associate Medical Lead Learning Disabilities and Specialist Adult Services, Avon & Wiltshire Partnership NHS Trust; Dr Juli Crocombe, Consultant Psychiatrist, St George's Hospital, Stafford; Ms Jackie Dziewanowska, Autism Spectrum Disorder Nurse Consultant, Nottinghamshire Healthcare NHS trust; Clinical Lead, Nottingham City Asperger Service; Ms Annie Foster-Jones, Autism Specialist Nurse, Cheshire & Wirral Partnership NHS Foundation Trust, Learning Disabilities Clinical Service Unit; Dr Marga Hogenboom, General Practitioner, Aberdeen; Professor Patricia Howlin, Professor of Clinical Child Psychology, King's College London; Consultant Clinical Psychologist; Mr Campbell Main, Lay member (representing service user and carer concerns); Ms Melissa McAuliffe, Asperger Specialist – Social Care, Rehabilitation & Recovery Team, East London NHS Foundation Trust; Mr Richard Mills, Director of Research, The National Autistic Society; Honorary Secretary and Research Director, Research Autism, London; Ms Joan Panton, Lay member (representing service user and carer concerns); Ms Maggi Rigg, Advisory Board Member, Cambian Group, London; Ms Anya Ustaszewski, Autism and Disability Awareness Trainer and Rights Advocate; Musician and Composer (freelance); representing service user and carer concerns

Financial Disclosures/Conflicts of Interest

To minimise and manage any potential conflicts of interest, and to avoid any public concern that commercial or other financial interests have affected the work of the GDG and influenced guidance, members of the GDG must declare as a matter of public record any interests held by themselves or their families which fall under specified categories. These categories include any relationships they have with the healthcare industries, professional organisations and organisations for people with autism and their families/carers.

Individuals invited to join the GDG were asked to declare their interests before being appointed. To allow the management of any potential conflicts of interest that might arise during the development of the guideline, GDG members were also asked to declare their interests at each GDG meeting throughout the guideline development process. The interests of all the members of the GDG are listed in Appendix 2 of the full version of the original guideline, including interests declared prior to appointment and during the guideline development process.

Guideline Status

This is the current release of the guideline.

Guideline Availability

Electronic copies: Available from the National Institute for Health and Clinical Excellence (NICE) Web site [   ].

Availability of Companion Documents

The following are available:

- Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. Full guideline. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 June. 424 p. (Clinical guideline; no. 142). Electronic copies: Available in Portable Document Format (PDF) from the National Institute for Health and Clinical Excellence (NICE) Web site ⬚.
- Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. Appendices to full version. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 June. (Clinical guideline; no. 142). Electronic copies: Available in Portable Document Format (PDF) from the NICE Web site ⬚.
- Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. Clinical case scenarios. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 June. (Clinical guideline; no. 142). Electronic copies: Available in Portable Document Format (PDF) and Powerpoint format from the NICE Web site ⬚.
- Autism in adults. Electronic audit tools. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 Jun. (Clinical guideline; no. 142). Electronic copies: Available from the NICE Web site ⬚.
- Autism in adults. Clinical audit tools. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 Jun. (Clinical guideline; no. 142). Electronic copies: Available from the NICE Web site ⬚.
- Autism in adults. Baseline assessment tool. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 Jun. (Clinical guideline; no. 142). Electronic copies: Available from the NICE Web site ⬚.
- Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. Costing statement. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 June. 24 p. (Clinical guideline; no. 142). Electronic copies: Available in Portable Document Format (PDF) from the NICE Web site ⬚.
- Autism in General Practice. Online education tool. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 Jun. (Clinical guideline; no. 142). Available from the NICE Web site ⬚.
- Autism overview. NICE pathway. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 Jun. (Clinical guideline; no. 142. Available from the NICE Web site ⬚.
- Autism in adults. AQ-10 test. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 Jun. (Clinical guideline; no. 142). Electronic copies: Available from the NICE Web site ⬚.
- The guidelines manual 2009. London (UK): National Institute for Health and Clinical Excellence (NICE); 2009 Jan. Electronic copies: Available in Portable Document Format (PDF) from the NICE Archive Web site ⬚.

Patient Resources

The following is available:

- Diagnosing, supporting and caring for adults with autism. Understanding NICE guidance. Information for people who use NHS services. London: National Institute for Health and Clinical Excellence (NICE); 2012 Jun. 16 p. Electronic copies: Available from the National Institute for Health and Clinical Excellence (NICE) Web site ⬚.

Please note: This patient information is intended to provide health professionals with information to share with their patients to help them better understand their health and their diagnosed disorders. By providing access to this patient information, it is not the intention of NGC to provide specific medical advice for particular patients. Rather we urge patients and their representatives to review this material and then to consult with a licensed health professional for evaluation of treatment options suitable for them as well as for diagnosis and answers to their personal medical questions. This patient information has been derived and prepared from a guideline for health care professionals included on NGC by the authors or publishers of that original guideline. The patient information is not reviewed by NGC to establish whether or not it accurately reflects the original guideline's content.

NGC Status

This summary was completed by ECRI Institute on August 30, 2012.

The National Institute for Health and Clinical Excellence (NICE) has granted the National Guideline Clearinghouse (NGC) permission to include summaries of their clinical guidelines with the intention of disseminating and facilitating the implementation of that guidance. NICE has not yet verified this content to confirm that it accurately reflects that original NICE guidance and therefore no guarantees are given by NICE in this regard. All NICE clinical guidelines are prepared in relation to the National Health Service in England and Wales. NICE has not been involved in the development or adaptation of NICE guidance for use in any other country. The full versions of all NICE guidance can be found at www.nice.org.uk ⬚.

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